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Organizing Your Child's Lab Results
by Susan Agrawal

Children with complex medical issues often need frequent monitoring of their blood, urine, and other bodily substances to ensure they are healthy. For example, a child on a certain medication may need liver function blood testing done periodically to make sure that the medication is not affecting his liver. Another child may struggle with anemia and need her hemoglobin and hematocrit measured. Still another may need frequent urine tests to check for protein.

While children routinely get many labs done at a time, you are probably aware that it is more important to keep track of certain ones than others. For example, my daughter routinely gets a Complete Blood Count (CBC) and Complete Metabolic Panel (CMP) at least every three months. While the total number of tests in these two panels spans a full page, we only keep track of the 16 most important parameters. In her case, these include liver and kidney function tests, red and white counts, hemoglobin, hematocrit, platelets, retic count, ferritin, CO_2, and albumin.

Lab results are simply a snapshot in time, and any one result may or may not mean anything, whether it is normal or abnormal. What is most important is to look at the trends over a long period of time. By looking at the trend, you are able to establish what is "normal" for your child, and you will have a much better sense when something may be changing.

There are a variety of ways to organize lab results to be able to see these trends. The easiest is to just use a spreadsheet or database program like Microsoft Excel, along with its associated graphing capabilities. Other options include using an online medical storage system, such as Google Health or Microsoft HealthVault. These online systems also allow access to other associated storage systems. Finally, your child's doctor or hospital may be using electronic medical records that you can access through a patient portal or personal health record.

Organizing Using Excel or Similar Programs

It is very simple to create a spreadsheet of lab values using Excel or a similar program. All you need to do is create a new document, decide what lab values to track, and enter in your results. I put the tests in the left-most column, and then have the lab values listed by

date in successive columns. Then I can track changes in a specific test over a long period of time.

I also find using the chart function very helpful. It is possible to select data and then turn it into a line graph, thereby visually displaying changes over time. This visual representation can really help you to determine subtle changes over time. For example, my daughter's CO_2 levels, while still normal, have been gradually rising over the past two years. I did not realize this until graphing them in a line graph. Now I know to keep a closer eye on them.
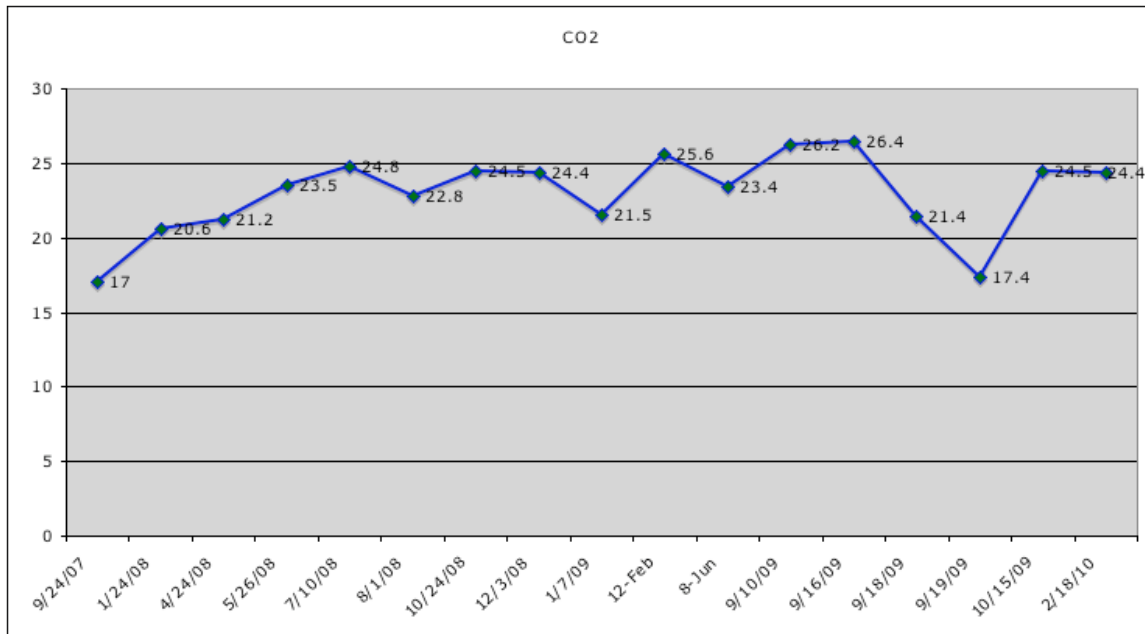
Organizing Using Google Health

Google Health is a free service that allows you to keep track of your health-related information online. The advantage to keeping your records online is that you can access them wherever you are, as long as you have an internet connection.

Anyone with a Google ID, which is available free at http://www.google.com/accounts, is able to use the Health storage system. This system allows you to enter a profile for each member of your family, including height/weight, medications, conditions, allergies, immunizations, and medical images. You can also manage lists of doctors and import information from select pharmacies, such as CVS and Walgreens, and even import data from Quest labs.

While good in theory, the program still has some quirks and clearly was not developed for children who are medically complex. Several of my daughter's conditions were not even listed in their databank (though they do allow you to add them manually). In

addition, when entering medications there is no option for choosing them to be administered by G tube or any other type of feeding tube.

Google Health allows you to input laboratory values in a table-style format. It will also graph the results for you. While this system works well, I found it tedious to enter the results. Each result must be entered individually, including selecting the test, selecting the date from the calendar, selecting the result, and selecting the units. It took me more than a minute to input each result, which is a very large amount of time when you are tracking multiple results. A batched input screen would be much more helpful.

Organizing Using Microsoft HealthVault

HealthVault is another service similar to Google Health that is free to anyone with a Windows Live ID. As a Mac user, I did not have an ID and found it quite a tedious process to get one. Once I finally got into the program, I found it slightly better designed for a child who is medically complex. Once again, you can set up a separate profile for each family member, including allergies, conditions, immunizations, procedures, lab results, medications, and doctors. The original screen is clearly set up for an older adult, with the values in the "Measurement" section intended for someone with typical adult conditions like high blood pressure, diabetes, and obesity.

The medication section in this program works a bit better, allowing you to select administration by feeding tube, but not allowing some of the more unusual administration methods, such as into the bladder. They had more conditions available to choose from, including several that were not listed in Google. Medication records can be imported from major pharmacies, and additional health tools allow integration between services such as MedicAlert.

Entering lab values was even more tedious with this program, and there is no graphing function available. You are able to flag results and enter additional information about each test, but the process of entering data was so laborious that I quickly gave up.

Facility-Based Patient Portals or Personal Health Records

It is becoming more common for hospitals, large outpatient groups, and other facilities to create a patient portal or personal health record, which is a password protected collection of your health information associated with that facility. In this situation, all your child's lab results may be sent to the patient portal and stored there. You can access them as needed from any computer using your password.

Because different facilities use different software programs, it is difficult to generalize about these storage systems. But it is definitely worthwhile to see whether or not your hospital and doctors have this type of system.

The Importance of Organizing Labs

While I have found it much easier to identify trends by organizing lab results, another major benefit has been the ease of sharing this information with my daughter's doctors. We used to go to appointments and watch her doctor digging through paper records, one by one, reading off the respective values on each one. It was tedious and time-consuming, and often left all of us with a pretty muddy picture of what was going on.

Now, I simply bring my spreadsheet of lab values, and the doctors can easily see exactly how she is trending over a period of several years. It has definitely simplified her care and our ability to make appropriate decisions for her treatment.